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Good afternoon Senator Crisco, Representative Megna and members of the Insurance and Real Estate Committee. I am here to testify in support of HB 5517, AN ACT CONCERNING COST-SHARING FOR PRESCRIPTION DRUGS, SB 371, AN ACT CONCERNING THE USE OF EXPERIMENTAL DRUGS, and SB 367, AN ACT CONCERNING SEVERE MENTAL AND EMOTIONAL IMPAIRMENT AND WORKERS' COMPENSATION COVERAGE.

The price of prescription drugs is creating an unsustainable burden on many Connecticut citizens and HB 5517 would cap these costs to \$100 per drug per month. The average annual cost of a specialty pharmaceutical drug is higher than the national annual median income¹. It is unfortunate that states cannot actually affect the prices of these drugs, but they can offer some financial relief for patients. This bill would certainly provide a meaningful incentive for insurers to do a better job negotiating with the pharmaceutical companies.

I would urge you to add to this legislation the transparency provisions that some other states are considering. The pharmaceutical companies claim that these astronomical prices are justified because they spend large sums on research and

¹ <https://www.washingtonpost.com/news/wonk/wp/2015/11/20/specialty-drugs-now-cost-more-than-most-household-incomes/>

development. If the prices are in fact justifiable, these corporations should not object to this transparency. The pharmaceutical companies should be willing to disclose manufacturing, production, research and development costs as well as profits and the costs to them of patient assistance programs. I will provide the committee with a chart created by the Senate Democrats' policy department regarding other states' actions on these issues². Even more recently, the governor of New York has included in his budget a proposal to cap the prices and require disclosure. The Attorney General of Massachusetts is investigating the possibility of bringing an unfair trade practice suit against Gilead Sciences (the maker of the Hepatitis C drug Solvadi). California will have a ballot measure that would, among other things, cap the price that the state would pay for prescription drugs at the rate that the VA pays. The VA, unlike Medicare, is permitted by law to negotiate drug prices with the pharmaceutical industry. I am including a chart that shows the difference between the VA price and the Medicare price on certain prescription drugs.³ While federal action on drug prices would be most desirable, that does not appear likely. I believe it is time for our state to act; HB 5517 would provide significant relief for many Connecticut citizens and I urge the Insurance and Real Estate Committee to pass this legislation.

SB 371 would offer hope to terminally ill patients who suffer from diseases for which there is no effective approved treatment. This legislation is similar to HB 5270 which was heard in the Public Health Committee. Unfortunately, recent federal court decisions have held that terminally ill patients do not have a right to try experimental

² Also this article is a summary <http://www.pewtrusts.org/en/research-and-analysis/blogs/stateline/2015/07/02/states-limiting-patient-costs-for-high-priced-drugs>

³ <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC4451044/>

treatment⁴. As a response to these decisions, a number of states have passed “right to try” laws to give these patients access to potentially life-saving therapy. The legislation before you would allow drug and device manufacturers to make investigational drugs and devices available to certain terminally ill patients. This would allow qualifying patients access to experimental treatments. Qualifying patients must have considered all other treatment options currently approved by the FDA, been unable to participate in a clinical trial for the terminal illness within 100 miles of home, received a recommendation from the treating physician for the experimental treatment, and have given written, informed consent. The legislation also prohibits any cause of action against the pharmaceutical company for harm done by a drug given in this situation.

While some argue that access to experimental treatments poses a significant risk of harm to the patient, it would seem that this danger is far less than that posed by the certain death due to the underlying illness. This bill strikes a reasonable balance; it contains numerous safeguards and allows access to these treatments only to terminally ill patients. It does not require that insurance companies cover these treatments, and it allows but does not require the manufacturer to make the products available. I urge the Insurance Committee to pass this legislation which would offer hope to patients afflicted with terminal illness.

SB 367 would ameliorate some of the unfortunate changes made to the workers’ compensation law in 1993. Specifically, it would expand workers’ compensation coverage to certain individuals (police officer) suffering from a mental or emotional impairment as a direct result of witnessing the death or maiming of another human being whose death or maiming was

⁴ Abigail Alliance for Better Access to Developmental Drugs v. von Eschenbach, 495 F.3d 695, 696 (D.C. Cir. 2007) (en banc), *cert. denied*, 128 S. Ct. 1069 (2008).

caused by an act of a person. I am pleased that this bill does not limit the coverage to an intentional act; it would seem that a person's mental impairment would not depend on whether or not the act she or he witnessed was intentional. Ideally, the legislation would be expanded to include other first responders in addition to police officers which would be similar to the language in SB 134.

In recent years medical science has made it increasingly clear that a mental health impairment can be as disabling as a physical impairment. Unfortunately, our current statutes do not reflect this new understanding. This bill would require that the worker be diagnosed by a psychiatrist or psychologist who must determine that the impairment originated from witnessing the death or maiming or the immediate aftermath of the death or maiming. The immediate aftermath is limited to six hours after the scene is secured by law enforcement. The visual witnessing must also be causally connected to the employee's employment. Passage of this bill would allow workers who are suffering from specific work related mental trauma to benefit from workers' compensation. This would be a positive change and would bring our statutes in line with the modern understanding of mental health.

Again, I want to thank the Insurance Committee for hearing bills on these crucial issues.

Table 2 Annual costs of multiple sclerosis disease-modifying therapies in the United States relative to cost estimates from other countries and the US Department of Veterans Affairs

	US Medicaid ^a	US VA ^b	Canada ^c	Australia ^d	UK ^e
Interferon- β -1b (Betaseron)	\$49,146	\$10,583	\$18,218	\$11,174	\$12,018
Interferon- β -1a IM (Ayonex)	\$49,837	\$30,273	\$18,641	\$12,641	\$14,113
Glatiramer acetate (Copaxone)	\$47,253	\$34,635	\$14,779	\$13,107	\$11,124
Interferon- β -1a SC (Rebif)	\$53,032	\$30,451	\$22,267	\$12,641	\$17,550
Natalizumab (Tysabri)	\$51,306	\$36,485	\$33,651	\$22,505	\$22,510
Interferon- β -1b (Extavia)	\$41,078	\$22,821	\$16,456	\$11,174	\$12,018
Fingolimod (Gilenya)	\$50,965	\$41,269	\$28,287	\$27,742	\$31,810
Tecifunomide (Aubagio)	\$45,970	\$35,357	Price pending	\$22,454	\$22,458
Dimethyl fumarate (Tecfidera)	\$50,573	\$40,704	\$21,510	\$22,547	\$29,711 ^g

Abbreviation: UK = United Kingdom; VA = Veterans Affairs.

^a Acquisition cost estimate as of December 2013 includes 23% Medicaid rebate.

^b Source: Available at: www.pbm.va.gov/PBM/PharmaceuticalPrices.asp (big 4 pricing listed for drugs except Rebif, where federal supply schedule pricing is listed). Accessed August 11, 2014.

^c Source: Available at: www.health.gov.on.ca/en/pro/programs/drugs/odbf/odbf_except_access.aspx. Accessed August 21, 2014.

^d Source: Available at: <http://www.pbs.gov.au/pbs/home>. Accessed August 21, 2014.

^e Source: British National Formulary. 66th ed. UK: BMJ Publishing Group; 2013-2014.

^f Funding decision under review at Ontario Public Drug Programs.

^g Source: Available at: www.mins.co.uk/news/1281928/Depth-Tecfidera-dimethyl-fumarate-new-oral-MS-treatment. Accessed August 21, 2014.